Depression in carers of people with dementia from a minority ethnic background: Systematic review and meta-analysis of randomised-controlled trials of psychosocial interventions

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ABSTRACT

Objectives: Systematic review and meta-analysis to determine the effectiveness of interventions in reducing depressive symptoms in ethnic minority carers of people with dementia.

Methods: We systematically searched EMBASE, CINAHL, MEDLINE, PsycINFO, PsycARTICLES, Applied Social Sciences Index and Abstracts (ASSIA), The Cochrane Central Register of Controlled Trials (CENTRAL), Sociological Abstracts and Social Policy and Practices databases from 1990 to 2015, supplemented by a grey literature search, hand searches of bibliographies and contacting authors. Study quality was assessed independently by two researchers using The Effective Public Health Practice Project Quality Assessment Tool, with an inter-rater reliability of Cohen's kappa of 0.72 (95% CI=0.42 to 1.01). Narrative synthesis and meta-analysis was used to assess intervention effectiveness. Meta-regression was used to assess whether factors such as intervention type, peer support, and ethnicity accounted for hetereogeneity.

Results: Thirteen studies were eligible for inclusion, with 1076 participants in control groups and 980 participants in intervention groups, 12 studies provided estimates for meta-analysis. All studies were from the USA. Interventions were associated with an overall mean reduction in depression in caregivers (SMD -0.17 (95%CI -0.29, -0.05; p=0.005). Meta-regression did not indicate any potential sources of heterogeneity, although narrative synthesis suggested that interventions developed with the target ethnic minority group's preferred mode of engagement in mind alongside cultural adaptations may have enhanced effectiveness.

Conclusions: Psychosocial interventions for depression in ethnic minority carers of people with dementia are effective and could be enhanced through cultural adaptations. High-quality studies targeting minority ethnic groups outside of the USA are needed.

Key words: *Ethnic minority; race; carer/ caregiver; dementia; depression; randomised controlled trials; RCTs*

Four key points:

- There is limited evidence on which, if any, community-based intervention is effective in reducing depressive symptoms in minority ethnic care-givers of people with dementia. This systematic review addresses this gap in knowledge.
- Interventions across a variety of modalities (psychological, multi-component and educational) improved depression in caregivers, with a summary effect size of SMD -0.17 (95%CI -0.29, -0.05; p=0.005) overall.
- Meta-regression analyses did not indicate that any specific factors such as the type of therapy (psychological, multicomponent or educational), the presence of peer support, the ethnicity of the group receiving the therapy, whether the person delivering the intervention was of the same bicultural/ bilingual background, or study quality accounted for heterogeneity across estimates, however in narrative synthesis basic levels of cultural adaptation of interventions (for example, translating generic materials or having bilingual/bicultural staff) appeared less effective than interventions that were developed with the target ethnic minority or cultural group's preferred method of engagement in mind.

- All eligible interventions (RCTs) were based in the USA. There is an urgent need for well-designed evaluations of interventions from other international contexts.

INTRODUCTION

Dementia is among the world's leading causes of death, disability and dependency in older people.[1,2] As ethnic minority groups in high-income settings age, the prevalence of dementia in ethnic minority populations is projected to rise.[3-5] There are concerns that ethnic minority elders may be underrepresented in dementia services, mental health services and in research.[6-9] Minority ethnic groups may also access dementia services later in their illness.[10] A late or a missed dementia diagnosis delays access to support, increases carer strain and can lead to individuals eventually presenting to services in crisis.[6,11] People with dementia from a minority ethnic background are also more likely to live in their homes rather than in 24-hour care homes.[6] For example, in Australia, a third of people living with dementia who lived in their homes were from minority ethnic backgrounds compared to 19% in care homes[12]; in the USA, nursing homes are significantly underused by minority ethnic groups in comparison to their non-Hispanic white counterparts.[13] Therefore, the carer role, which impacts individuals in all aspects of their lives, is largely provided by partners, family and members of the community.[14]

Generally, caregivers have reported higher perceived stress and depressive symptoms than non-caregivers.[15,16] Studies have shown that this is more severe for carers from minority ethnic backgrounds along with having higher unmet needs than reference populations. [17-19] High psychological distress for minority ethnic carers is associated with poor outcomes for people with dementia from minority ethnic backgrounds, which is particularly concerning as there is very little to no research investigating their experiences.[7] Therefore, stress associated with caregiving, whether isolated, or over time, has the potential for having lasting negative effects on care-givers and is associated with an

increased likelihood of experiencing depression. [15,20-23] Existing evidence supports the use of non-pharmacological interventions to reduce carer strain and depression for the benefit of both the carer and the person with dementia.[24,25] However, the low uptake of formal services by minority ethnic groups reveals barriers to accessing care, and with increased emphasis on community and social support by governments and health bodies, the impact of caregiving will be much greater for minority ethnic groups.[1,26] Therefore, there is a need for community-based care that can address these barriers such as concerns around appropriate care that reflects religious and cultural needs, the stigma of a dementia diagnosis, low awareness of dementia, the perception of symptoms as normal ageing or due to other causes and attitudes around not wanting outside involvement or not seeing a need for it.[10,27]

Despite the strong policy and research recommendations acknowledging the disparity in wellbeing, [1,28] there is very little information on effective community-based care for depression in western countries for minority ethnic carers.[6,22] Therefore, in this systematic review we aimed to assess the effectiveness of community-based randomised controlled trials (RCTs) of psychosocial and educational interventions in minority ethnic care-givers of people with dementia. Based on the original questions in our registered protocol (PROSPERO 2014 CRD42014007418) the aim of this review was to determine:

1. Which psychosocial interventions reduced symptoms of depression in minority ethnic carers of people with dementia
2. Of those effective psychosocial interventions identified, what specific factors made these interventions more suited to the needs of carers from minority ethnic backgrounds.

METHODS

Search methods

Relevant studies were identified by searching titles and abstracts in the following bibliographic databases: EMBASE, CINAHL, MEDLINE, PsycINFO, PsycARTICLES, Applied Social Sciences Index and Abstracts (ASSIA), The Cochrane Central Register of Controlled Trials (CENTRAL), Sociological Abstracts and Social Policy and Practice. If any identified papers were not retrievable, the authors were contacted to request copies. All first authors of included studies were contacted for unpublished studies.

Searches were conducted between 1990-2015. The search strategy included terms that were expanded using Medical Subject Headings (MeSH) terms. Search strategies were developed with the assistance of a librarian. Examples of search terms included “dementia”, “ethnic groups”, “community health services”, “psychosocial”, “awareness”, “intervention” and “carer”. See Supplementary Material 1 for the search strategy for MEDLINE. This was modified for each database to fit subject headings and search terminology.

Initial screening of abstracts and full text screening were carried out by RP and VR independently, with consensus achieved for unclear studies through discussion with JDM. During an additional full-text screening of papers, RCTs with depression as an outcome were identified by NA and checked with JDM. No restrictions were placed on language. A grey literature search to 2014 was also conducted by RP.

The protocol for the systematic review was registered on PROSPERO (CRD42014007418).

Criteria for study selection

Types of studies

Included studies had to be randomised controlled trials (RCTs) with a control or a comparison group. Control groups were classified as 'any other treatment', or 'treatment as usual'. Studies with multi-arm interventions were included if they met inclusion criteria. No restrictions were placed on quality of studies or on the duration of each trial, as long as baseline and follow-up data were recorded. Interventions had to be carried out in a community-based setting such as in homes, neighbourhoods, schools, places of worship and voluntary agencies.

Types of participants

Included participants were carers of persons with dementia from minority ethnic backgrounds. For the purpose of this review, 'minority ethnic' was defined as the "common geographic origins, ancestry, family patterns, language, cultural norms and traditions, and the social history of particular groups" [29], and groups which experienced a cultural heritage distinct to the majority population.[30] Carers were defined as a close friend or family member that provided support to the person with dementia. Studies that included data on minority ethnic groups exposed to an intervention that had also been provided to the majority population, were similarly extracted. The person with dementia was considered to be anyone diagnosed with a possible or probable dementia e.g. Dementia in Alzheimer's disease, Lewy Body Dementia, vascular dementia and frontotemporal dementia.

Types of interventions

Community-based studies which either provided psychological interventions for depression and/ or psychosocial interventions providing emotional support, information,

education to increase awareness, interventions promoting help-seeking behaviour and psychosocial functioning on a group or individual level, were included. 'Community-based' was defined geographically as a location or setting that was not in an institutional setting.[31]

Outcomes

Studies with validated measures for depressive symptoms at baseline and in the follow-up period were included to determine the severity of depressive symptoms and assess the effectiveness of interventions on improving care-giver depression. Change scores were derived (by subtracting follow-up scores from baseline).

Data extraction and quality assessment

Data was extracted for all studies and entered into a structured form with items: author, year, ethnicity, study location or context, length and frequency of the intervention and follow-up periods and reported outcomes relevant to objectives. Data extraction was conducted and cross-checked between two researchers (RP and NA), with disagreements resolved by discussing with one of the other investigators (JD). The Effective Public Health Practice Project Quality Assessment Tool (EPHPP) for quantitative studies was used for quality assessment as it has been specifically designed to review public health programs.[32] It has good construct validity and inter-rater reliability (ICC=0.77, 95% CI 0.51-0.90).[33] The interventions' ease of accessibility to participants could not be directly assessed through the EPHPP tool. To determine barriers and facilitators for minority ethnic carers to accessing and engaging with interventions and the absence or presence of cultural adaptations, topic guides from existing literature were utilised.[22,34] Examples include but are not limited to: logistical barriers, language, familism and stigma. Others were identified upon reviewing the

included papers. Quality assessment was conducted by RP and NA. A 14% sample of papers were assessed by NA blind to the quality assessment scores made by RP had an inter-rater reliability of Cohen's kappa of 0.72 (95% CI: 0.42 to 1.01), indicating a good level of agreement. [35] The included RCTs were rated on six domains (A-F), as either strong (1), moderate (2) or weak (3); based on a series of questions in each category: (A) selection bias, (B) study design, (C) confounders, (D) blinding, (E) data collection and (F) withdrawals/dropouts. See Supplementary Table 3 for a complete breakdown of quality ratings.

Narrative synthesis

A narrative synthesis was conducted to assess the diverse range of contexts, study characteristics and participants.[36] To capture the commonalities across interventions, studies were grouped by their intervention type i.e. psychological, multi-component (if involving multiple elements) or educational, with 'vote counting' used to inform initial synthesis.[36,37] To explore relationships, studies were grouped into intervention type and then ordered by quality rating. Similarities across grouped characteristics such as ethnicity of participants, mode of delivery (e.g. one-to-one vs. tele-support vs. peer support) and location (e.g. in-home vs. local area), were also noted.

Statistical analysis

We performed random effects meta-analysis across studies utilising Standardised Mean Differences (SMD) in depression measures, to account for the different scales used across studies, with an assessment of I^2 for study heterogeneity. Meta-analysis procedures in Stata/MP 13.1 were employed utilising the *metan* suite of commands. As some of the estimates derived from the same investigator (Belle et al. 2006) or research group (REACH),

the *robumeta* suite of commands were utilised to account for clustering of estimates by investigator or research team, leading to robust standard error estimation as a form of sensitivity analyses.

Finally, we utilised meta-analysis regression (meta-regression) to assess characteristics of studies in potentially accounting for statistical heterogeneity. In particular we assessed: intervention type (psychological, educational or multi-component), presence of peer support, ethnicity, whether the person delivering the intervention was of the same bicultural/ bilingual background as the recipient, quality of the study and whether the control condition adequately adjusted for contact time and type of delivery adequately.

To assess for publication or small study biases we created a funnel plot and utilised Egger's test to assess for small study effects.[38]

RESULTS

The searches produced a total of 13,422 titles and abstracts. The majority of papers for which full copies were retrieved and assessed were from the USA, with some papers from Canada and the UK however these papers did not meet the inclusion criteria; for example, an intervention for a South Asian community from the UK was excluded because it was not a randomised controlled trial ('Meri Yaadein')[39] and a technology-based trial from Canada[40] was excluded because it was not randomised and did not have depression outcomes. There were no additional trials identified through the grey literature searches. The flow diagram for study inclusion is displayed in Figure 1.

[FIGURE 1 HERE]

Demographic characteristics

Table 1 provides an overview of studies. In total, there were 2056 participants across interventions (range of 14–642 participants across studies), of which 980 were randomised to the intervention and 1076 to a control. Six interventions were delivered to participants from a minority ethnic background, the remaining seven were delivered to a mixed population. All studies were set in the USA and participants were identified as Latina/Latino American, African American, Chinese American and 'other'. White or White Non-Hispanic American carer data was extracted for comparison with minority ethnic data where possible. Carers had a mean age of 59.09 years (SD=11.36) and female carers made up 86.0% of the total sample (Table 1). Forty-one percent of primary carers were spouses. Persons with dementia had a mean age of 79.39 years (SD=8.8) and mean Mini Mental State Examination (MMSE) score of 13.13 (SD=7.75) with a range of 12.8 to 13.59, indicating moderate levels of dementia severity.

Quality of the studies

Nine of the thirteen studies had a 'strong' quality rating (Table 1), with additional training provided to outcome assessors and to staff delivering the intervention. Those that concealed participant allocation had independent and/or masked assessors, however in most studies it was not possible to mask participants, due to the nature of the intervention being delivered.

[TABLE 1 HERE]

Overview of interventions

Seven interventions had a clear psychological therapy component (e.g. cognitive behavioural therapy or family therapy) and were categorised as 'psychological therapies'; five interventions were classified as 'multi-component' as they included various components including targeted stress management and problem solving,[41-45] with individual or group support, [41,44,45] as well as assisting care-givers to effectively access appropriate community/ health services.[43] One intervention was classified as 'educational' as this was the main focus.[46]

Four of the interventions were delivered in-home[43,47-49]; four were delivered with peer support via videoconferencing or group sessions[45,50-52]; two interventions provided a psychoeducational resource[46,53] and three had a combination of components in their delivery.[41,42,44]

Study personnel

Eleven out of the thirteen studies had direct contact with personnel: a trained interventionist, social worker or a counsellor. The remaining two used non-interactive resources, such as DVDs or other media.[46,53] Twelve studies reported that staff and professionals had the same bicultural/ bilingual backgrounds as the participants.[41-44,46-53] Investigators in all thirteen of the studies provided training for the interventionists, with some providing a detailed intervention manual and certification. In most studies, supervisory meetings were held to monitor progress and performance, and to give feedback. Across most studies, people delivering the intervention had formal training and experience of working in their respective fields. See Supplementary Table 1: 'Included studies' personnel' for more information.

Depression measures

Nine of the thirteen studies investigated depressive symptoms as a primary outcome, [41,45-50,52,53] one study as a secondary outcome[43] and two studies did not specify assessing depression, but still assessed this.[42,44]. Depressive symptoms were reported using both the English and Spanish versions of The Center for Epidemiologic Studies Depression Scale (CES-D; 20-item and 10-item) and The Patient Health Questionnaire (PHQ-9). Post-test follow-ups ranged from 5 weeks to 6 months (see Table 2). Six studies reported having more than one follow-up assessment which ranged from 6 months to 18 months after baseline assessments.

Effects of types of interventions on depression

Psychological therapies

There were six interventions using cognitive-behavioural therapy (CBT) and one using family therapy combined with an in-home videophone.[47-53] CBT combined with peer-support was a common component in effective interventions particularly for Hispanic or Latin American carers.[49-51]

Educational

Gallagher-Thompson, Tzuang, Hinton, Alvarez, Rengifo, Valverde, Chen, Emrani, Thompson [46] provided a “fotonovela” (photo novel) to Mexican-American carers, in a study design which had a ‘strong’ quality rating, which reported significant improvements to post-intervention CES-D scores. Through a friendship between female Mexican-American carers, the fotonovela demonstrated activities that promoted self-care, respite, communication, help-seeking, dealing with problem behaviours and home adaptation for dementia care. The

fotonovela was readily available online and compared to the control, carers were found to refer to the fotonovela more often and were more likely to share it with family and friends.

Multi-component

All the multi-component studies predominantly had African-American and Hispanic or Latin American carers as participants, and all control groups were mailed basic educational materials.[41,42,44] These interventions comprised a combination of approaches which included targeted stress management and problem solving, peer support and assisting caregivers to access services/ health seek more effectively. These interventions were less focused on psychological treatments for depression, although may have contained some elements of these approaches.

[TABLE 2 HERE]

Meta-analysis and assessment of publication bias

In random effects meta-analyses, interventions (psychological, multi-component and educational) to address depression in ethnic minority care-givers relative to the control condition, were associated with an overall mean reduction in depression scores (SMD -0.17 (95%CI -0.29, -0.05; p=0.005). Heterogeneity was negligible (I^2=0.0%, p=0.547) (Figure 2). Analyses were repeated using robust variance estimation to account for clustering of estimates either due to estimates deriving from the same study or due to correlation of estimates from studies being conducted by the same research group. These additional adjustments had a negligible effect on overall effect sizes (robust variance estimation to account for clustering of estimates derived from: 1. The same paper was SMD -0.16 (95% CI: -0.25, -0.07; p=0.003); 2. The same research group was SMD -0.16 (95% CI: -0.24, -0.08; p=0.005)).

Meta-regression did not indicate significant heterogeneity according to intervention type, instrument used to assess depression, presence of peer support in the intervention, ethnicity, whether people delivering the intervention were of the same bicultural/ bilingual background or according to the quality rating of the study (Supplementary Table 2). Only eight of thirteen trials were judged as adequately controlling for contact time and type of delivery effectively, whilst across the remaining studies, most control conditions did not take into account contact time, and instead provided a comparative condition which usually consisted of mailed educational materials and brief telephone support with bilingual staff. Therefore, this was also added to the meta-regression, to assess if this accounted for overall heterogeneity, however this was not found to be the case (Supplementary Table 2).

Overall, the size of the effect across the different intervention types (psychological, multi-component and educational) were broadly similar (Figure 2). Visual inspection of funnel plots did not indicate publication biases (Supplementary Figure 1), supported by Egger's regression test (Estimated bias coefficient: 0.67 (SE: 0.62) p=0.30).

[FIGURE 2 HERE]

Barriers and facilitators and benefits of the intervention for ethnic minority carers

A common theme across studies was that basic levels of cultural adaptation of interventions (for example, translating generic materials or having bilingual/bicultural staff) were less effective than interventions that were developed with the target ethnic minority or cultural group's preferred method of engagement in mind. In some studies, the development or adaptation of the intervention was enhanced in response to qualitative data, for example, Chinese-American carers were found to prefer in-home support

compared to Latin-American carers who appeared to have better outcomes in interventions utilising group or family-orientated approaches.[47,48,51]

Table 3 highlights barriers and facilitators for minority ethnic carers to accessing and engaging with interventions and the absence or presence of cultural adaptations. Many of the interventions were reliant on carers being active help-seekers as well as having some literacy, however, attempts were made to address lower literacy levels[46] and regular reminder phone calls to encourage engagement with materials[53]. The costs of some interventions were high for investigators to deliver, for example in studies utilising videoconferencing equipment and mobile phones. However, leaving the home was a common barrier for care-givers which was addressed through home visits, via technology or through materials such as DVDs (see Table 3).

Common facilitators included the translation of materials and employing bilingual staff however, identified papers went beyond this. For example, an attempt was made to address socio-political and historical contexts of language-use and differing dialects that may interfere with clinician-participant rapport. [48] There was also an emphasis on educational approaches which focused on de-stigmatising language use (e.g. using terms such as “memory problems” vs. “dementia”) to help overcome the stigma attached to attending therapy.[48-50,52]

Interventions that were specifically designed for the target ethnic or cultural group built on their literacy levels, preferred method of contact, social networks in the form of local organisations for recruitment and retention and recruited staff experienced with working with the target group, as highlighted in Table 2.[46,48,49] In most of the studies, investigators specified that staff received cultural sensitivity training, however it was unclear

what such training entailed (e.g. REACH I, Gallagher-Thompson, Coon, Solano, Ambler, Rabinowitz, Thompson [50]). Overall, across most studies, investigators acknowledged that ethnicity and cultural background could impact on carer engagement with interventions.

[TABLE 3 HERE]

DISCUSSION

This is the first systematic review and meta-analysis on the effectiveness of community-based interventions for depressive symptoms in minority ethnic carers of persons with dementia. In previous reviews, investigators have assessed the effectiveness of interventions on carer depression for dementia[15,54,55]; our review builds on this by specifically focusing on the needs of ethnic minority care-givers of people with dementia. The main findings of our review suggests that overall, community-based interventions are effective in reducing depressive symptoms in minority ethnic carers, through a range of intervention types, which include psychological, multi-component and educational interventions. Of note, psychological interventions specifically designed to target depressive symptoms in caregivers (such as CBT) seemed to have a similar effect in reducing caregiver depression as those interventions that incorporated other approaches (e.g. multi-component and educational interventions). Although we attempted to classify interventions into three groups based on the substantive features of the intervention (psychological, multi-component and educational), in reality many of the interventions shared common characteristics, which in practice may have meant that it was not possible to discern effective treatments by a pre-defined 'type'. This challenge of classifying interventions for care-givers of people with dementia has also previously been noted by other investigators working in this area,[55] and perhaps reflects the multi-faceted nature of depression in caregivers of people with dementia. A further shared factor across all of the included studies, was that investigators acknowledged that ethnicity and cultural background had a major impact on carer engagement with interventions and that this could be enhanced through cultural adaptations.

Despite our best efforts to include studies across international contexts, all reviewed studies were from the USA. This has been a concern noted in other reviews, which have also indicated that most studies have been from the US and are geographically restricted.[6,56] This is a major limitation of the evidence base as the migration and settlement circumstances of minority ethnic elders and their carers differ greatly across international contexts, as do the health systems in which interventions are delivered.[57,58]

The majority of included studies were limited to minority ethnic carers who identified as Hispanic/ Latin-American or African-American with little to no further clarification of subpopulations within these broad and highly diverse groups. Approaches to classify "race" or "ethnicity" have been shown to be problematic.[59,60] "Race" has previously been used as a "biological concept" referring to differences between populations[59] whereas "ethnicity" may refer to membership of groups identified through common language, culture, ancestry or traditions. In reality, both "race" and "ethnicity" are socially constructed, liable to change over time, context, studies and even across data systems. For the purposes of this review we employed the terms used by the authors of each of the studies to describe the specific ethnic/ racial groups, however such approaches may miss much of the cultural diversity within the employed categories.

Across all studies in the meta-analysis, the CES-D was used to screen for depressive symptoms. The Spanish version of the 20-item CES-D has previously been shown to have reasonable cross-cultural validity with Puerto Rican patients aged 50 and older from USA: sensitivity (95% CI)= 81% (65–91), specificity (95% CI)= 70% (68–72) with an optimal cutoff of 20.[61] However, the extent to which the CES-D is a gold-standard in cross-cultural contexts

is still in need of further investigation and so its interpretation and application should be given careful consideration.[62]

Translated information to suit the needs of culturally and linguistically diverse populations is vital to high quality healthcare provision.[63-65] However, most of the included interventions went beyond this to address the specific issue of low levels of help-seeking and engagement with services in ethnic minority groups.[10] For example, interventions aimed to enhance access to care by providing face-to-face support in the home, in local settings, or via DVDs, picture novels and video-conferencing, eliminating difficulties experienced when attending out-of-home support. These interventions also addressed language barriers by improving the quality of communication and cultural competence by having trained bicultural or bilingual staff (with regular supervision), with materials which had been developed taking into account literacy levels, dialects, language use and sensitivity to historical contexts unique to the target group. Attrition and low engagement levels were addressed through maximising existing support networks, by working with local organisations and charities, providing regular visits and reminder telephone calls. Many of the interventions built on familial and social networks, which enhanced standard approaches to treating depression in carers. A limitation of these interventions may be the cost particularly from the high number of resources attached to them such as additional training and ongoing supervision for interventionists and clinicians, the delivery and coordination of multi-component interventions and the provision and installation of technology i.e. videophones. Whilst it was beyond the scope of this review to assess outcomes other than depression, such approaches may have a beneficial impact on improving equity of access to secondary and specialist care for people with dementia from minority ethnic backgrounds, where this remains a concern.[10,22]

Strengths and limitations

There were a number of strengths to our review. We conducted extensive searches, which included the grey literature as well as peer reviewed manuscripts. We contacted authors of all included studies to ensure that unpublished findings were also included. Publication bias was also evaluated. We did not have any language restrictions to our searches, which would have minimised location biases. Our search strategies were developed with experts, and the protocol and objectives for the review was pre-registered on Prospero. All studies were quality assessed using a structured tool with a good level of reliability between two raters. A random effects meta-analysis was applied to the aggregate data along with an assessment of heterogeneity, and the impact of heterogeneity related to study quality on meta-analysis was further assessed through meta-regression. We also extracted and synthesised information relating to the facilitators and barriers to accessing treatments amongst ethnic minority groups and used this to inform narrative synthesis.

As previously highlighted, despite our best efforts which included an extensive search of the grey literature, we were unable to locate studies for inclusion outside of the US, which may limit the generalisability of the review's findings, but also highlights an urgent need to conduct studies in other settings, where health care systems and ethnic minority populations may differ greatly.

Conclusions

In conclusion, community-based interventions, including psychological, multi-component or educational interventions improve depression in ethnic minority carers of people with dementia, with similarities in magnitude of improvement across the different

intervention types. Culturally adapted interventions which take into account the specific circumstances of ethnic minority care-givers of elders with dementia may have a particular role to play for ethnic minority groups, as do interventions which practically address barriers to accessing treatments. Our review highlighted an absence of well-designed evaluations of interventions outside of the USA. Future research should aim to address this major limitation. Our review findings highlight the benefits of interventions which have been developed with specific cultural contexts in mind in ameliorating depression in ethnic minority care-givers of people with dementia.

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TABLE 1

Overview of included studies

Caregiver	**No. of studies (N)**	**(%)**
Caregiver gender		
Female only	4	31%
Male only	0	0%
All	13	%
Average caregiver age		
< 65 years	11	80%
> 65 years	2	20%
Person with Dementia		
Person with dementia age		
< 65	0	0%
≥ 65	13	100%
Dementia severity (mean MMSE score)		
> 10 (mild to moderate)	7	50%
≤ 10 (severe)	0	0%
MMSE score not reported	7	50%
Ethnicity		
African American	6	-
Chinese American	2	-
Latin / Hispanic American	8	-
Mexican	1	-
Cuban	1	-
Dominican	1	-
Puerto Rican	1	-
Not specified	6	-
Classified as "other"	2	-
White / Non-Hispanic White†	6	-
Country/States		
USA	13	100%
Sites: *California*	2	-
Los Angeles	1	-
Alabama	2	-
Tennessee	1	-
Florida	5	-
Pennsylvania	2	-
Massachusetts	1	-
Quality		
Strong	9	69%
Moderate	4	31%
Weak	0	0%

†Data included for comparison where available.

TABLE 2

Included studies: Description, quality assessment and main findings

Psychological therapies							
Study code (Context)	**Ethnicity, n**	**Length of follow-up**	**Measure**	**Intervention**	**Control**	**Quality rating**	**Results**
Eisdorfer, 2003 (REACH I)	Cuban American n=114 White non-Hispanic n=111	6m, 18m	CES-D	Two intervention types: 1. Family therapy that identified existing support structures/resources, increase family caregiving efforts to reduce primary caregiver burden. 2. Family therapy with optional videoconference when physical attendance impractical; connect caregivers to family members and support services.	3. Biweekly empathic telesupport and mailed educational materials.	STRONG	All conditions showed some reduction however no differences found between family therapy with videoconferencing compared to face-to-face family therapy or the telesupport control condition. Intervention 1: Group by time interaction showed caregivers had an increase in depression scores. 6m mean=18.02 (SD=12.8); 18m=18.34 (SD=12.5). Intervention 2: Overall showed a reduction for all. Further baseline and follow-up scores not provided. Mostly benefitted White non-Hispanic and Cuban-American individuals with>5-point reductions. 6m mean=17.31 (SD=10.5); 18m mean=17.49 (SD=10.55) Control: 6m mean=17.72 (SD=10.4); 18m= 18.14 (SD=10.4) By ethnic group: In Intervention 1 only Cuban-American individuals had reduced depression scores (over 5.5 points); Cuban-American husbands over 7.5-point increase. Intervention 2 was most effective for Cuban-American husband and daughter caregivers (over 5-point reduction at 18-month follow-up). In the control condition Cuban-American caregivers had increased their depression scores whereas White non-Hispanic caregivers showed a decrease.

Gallagher-Thompson, 2003 (REACH I)	Mexican American /Latina n=91 White n=122 (Female)	3m, 6m, 18m	CES-D	'Coping with Caregiving': CBT-based mood management in small groups to reduce negative affect, communicate assertively.	1. 'Enhanced Support Group' control guided by Alzheimer's Association manual to develop caregiver peer support. 2. Minimal support condition: empathic telesupport and mailed educational materials. *All active groups were in well-known/accessible community locations. Controls received weekly 2-hour sessions in 3-month intensive phase.*	STRONG	At baseline, 48% were at risk of clinical depression with scores above 16. 3-month outcomes were reported. Overall intervention was more effective than control. Peer-support with skill-building was more effective than peer-support alone or tele-support. Intervention: Latino intervention baseline mean=16.33 (SD=12.42), change score=-3.05. White intervention baseline mean=18.47(SD=11.67), change score=-2.32. Control: Latino control baseline mean=17.18 (SD=12.32), change score=-0.12. White control baseline mean=15.03(SD=11.24), change score=-0.34. No differences found by ethnicity.
Gallagher-Thompson, 2008	Hispanic/Latina n=89 Non-Hispanic White n=95 (Female)	6m	CES-D	CBT-based intervention 'Coping with Caregiving'. Twelve weekly two-hour small group sessions in local settings involving coping strategies, role-playing, self-care, end-of-life planning, accessing community resources.	Seven biweekly empathic calls lasting 15-20min; generic educational materials mailed to meet caregiver's needs.	STRONG	Overall, intervention was more effective than control. Hispanic/Latina group had a significant decrease in depression symptom scores for the control and intervention, non-Hispanic White group only for the intervention. Peer-support with skill-building was superior to biweekly telesupport. Intervention: Hispanic/Latina intervention baseline mean=14.83(SD=12.47), change score= -4.57. White non-Hispanic intervention baseline mean=15.14(SD=10.46), change score=-3.28. Control: Hispanic/Latina control baseline mean=15.64 (SD=13.60), change score= -2.81. White control baseline mean=13.39(SD=9.42), change score=-0.57. No overall differences found by ethnicity. Greater change score for Hispanic/Latina caregivers compared to White caregivers.

Gallagher-Thompson, 2007 (Study I)	Chinese American n=55 (Female)	3m or 4m	CES-D	Six in-home CBT-based behavioural intervention focusing on negative thinking, help-seeking, dealing with problem behaviours, family communication, end-of-life discussions.	Biweekly empathic calls targeting challenges and distress. Supplemented with mailed educational materials.	STRONG	Home-based CBT was more effective than the telesupport control. Intervention baseline mean=16.68 (SD=10.81), change score=-5.89. Control mean baseline=12.49 (SD=7.97), change score=-0.49.
Gallagher-Thompson, 2010 (Study II)	Chinese American n=70	3m	CES-D	CBT-based 90-min DVD (psychoeducational) focusing on coping skills, positive thinking and response, effective communication; role-play.	Educational DVD on dementia.	STRONG	Skill-building CBT-based DVD appeared more effective than the educational DVD Intervention baseline mean=13.03(SD=11.85), change score= -2.25. Control mean baseline=14.74 (SD=12.51), change score= -0.8. Treatment effect = F(1,68)=0.15, p=0.164.
Gonyea, 2012	Hispanic/Latina n=67 (Puerto Rican, Dominican, other)	5w, 6m	CES-D	'Circulo de Cuidado' (Circle of Care): Five weekly 90-min social worker led informal group skill-building sessions, based on peer support, with home assignments and four booster calls; behavioural strategies to reduce caregiver stress and dementia neuropsychiatric symptoms, increase individual with dementia's positive experiences/activities.	Same group format focused on educational peer support caregiving topics i.e. home safety, peer sharing, communication with professionals.	STRONG	Peer-support with skill-building followed up with telesupport appeared more effective than educational peer-support for Hispanic/Latina caregivers. Intervention baseline mean=14.39 (SD=6.14), change score at 5w from baseline= -0.6, at 6m= -0.57. Control mean baseline=14.41 (SD=6.31), change score at 5w= -0.03, at 6m= 0.03, F=9.74, p=0.01
Glueckauf, 2012 (Pilot RCT)	African American n=14	13w	CES-D	12-week face-to-face CBT in small groups; peer support to identify maladaptive thinking.	Same format in-home telephone-based CBT via teleconference system.	MODERATE	Intervention baseline mean= 11.80 (SD=7.40), change score=-2.8, p=0.23. Control baseline mean=12.67 (SD=8.91), change score=-8, p=0.03.
Multi-component							

Belle, 2006 (REACH II)	Black/ African American n=211 Hispanic/Latin American n=212 White n=219	6m	10-item CES-D	Twelve 1.5hr in-home, three telesupport and five telesupport group sessions focused on various strategies to manage stress and problem solve.	Brief check-in calls at 3 and 5 months. Mailed basic English/Spanish dementia information and caregiving/community resources.	STRONG	Clinical depression prevalence at baseline lower in intervention group, 12.6% (intervention) vs. 22.7% (control). Both conditions showed substantial reductions, however in-home visits, peer-support and telesupport appeared superior to basic information with telesupport. The intervention had greater reduction for both minority ethnic groups. Intervention baseline mean=10.1 (SD=6.7), change score=-2.6. Hispanic or Latin American caregiver's intervention baseline mean=10.9 (SD=7.2), change score=-2.4. African-American caregiver's intervention baseline mean=9.3 (SD=6.2), change score=-2.8. Control baseline mean=9.65 (SD=6.65), change score=-0.45. Hispanic or Latin American control baseline mean=10.4 (SD=7.3), change score=-0.8. African-American control baseline mean=8.9 (SD=6), change score=-0.1. The intervention appeared more effective for white non-Hispanic caregivers with increased reductions in comparison, 10.5% (White non-Hispanic) vs. 24.5% (Hispanic or Latin American and African-American).
Chodosh, 2015	African American White Latin American Other n=144	6m, 12m	PHQ-9	In-home and telephone-based care management; problem solving, increasing access to community and health services. Initial assessment determined priority problems.	Only telephone-based care management	MODERATE	‡Baseline mean PHQ-9 score: 5.1 (mild depression). Intervention and control conditions had a reduction in PHQ-9 scores. Both conditions, in-home and telephone-based care-management, were effective. 6m adjusted differences=0.36 [95% CI -2.00-2.73], p=0.76. 12m=-0.24, [95% CI -7.02-6.54] p=0.95. No between-group differences at 6m/12m.
Czaja, 2013	African American n=54	5m	10-item CES-D	Two in-home, four skills-based video lectures published monthly followed by five videophone support	1. Equivalent intervention contact time with an emphasis on nutrition	MODERATE	‡An in-home skills-based support system with video lectures did not appear to be superior to the same system with no skills-based support and an

Modelled on REACH II (see also Belle et al. 2006).	Hispanic n=56			groups targeting safety, social support, problem behaviours, depression, and caregiver health.	2. Mailed educational materials; received 15-min check-in call at 3 months.		information only condition. Some reduction detected in all conditions. Intervention baseline mean=9 (SD=5.8), change score=-0.9. Control baseline mean=9.8 (SD=6.6), change score=-0.7.
Burgio, 2003 (REACH I)	African American n=70 White n=70	6m, 12m, 18m	CES-D	Received 3-hour skills training, 'critical skills' videotapes, followed by in-home/telephone therapeutic skills support managing problem behaviours, caregiver stress, communication, problem solving.	Mailed educational materials for acute distress in months 1 and 3. Structured 15-min calls enquired after physical health and caregiving problems with basic information provided.	MODERATE	‡Some evidence for a skills-based training followed by in-home and telephone support being superior to an information only condition. Small reduction in both conditions. Only 6-month follow-up reported. Intervention baseline mean=14.60 (SD=9.99), change score=-1.67. Control baseline mean=14.48 (SD=10.57), change score=0.31. No differences reported by ethnicity.
Winter, 2006 (Academic collaboration with Supportive Older Women's Network	African American White (Female)	6m	CES-D	Weekly social-worker led teleconference linked five caregivers together in a peer support intervention for stress management.	Usual care. Details not reported.	STRONG	‡Overall, increased scores on the CES-D were noted in the intervention with a reduction only in caregivers 65 years or older. Intervention baseline mean=14.1 (10.80) change score=4.07. Control baseline mean=15.9 (SD=11.1), change score=4.3. No differences found by ethnicity.
Educational							
Gallagher-Thompson, 2015	Mexican American n=110	4m, 6m	CES-D	Spanish/English 20-page picture book (fotonovela) showed actors depicting challenging scenarios managing caregiver stress, problem behaviours and requesting help from family.	Publicly available pamphlet on managing caregiver stress, with monthly check-in calls.	STRONG	All follow-up mean scores reduced > 5 points. Picture book for Mexican-American caregivers appeared superior to the generic information leaflet. Intervention baseline mean=19.66 (SD=11.85), change score= -9.65.

	Control baseline mean=16.81 (SD=13.74), change score=-4.3. Follow-up pairwise comparisons showed intervention had significant decrease from baseline to 4m ($p<0.001$), from 4m to 6m ($p<0.002$). Reduction for control.

Key:
Cutoff scores by depression outcome measure: CES-D ≥ 16 = high risk; PHQ ≥ 5 = mild, ≥ 10 = moderate, ≥ 15 moderately severe, ≥ 20 severe depression.
‡Results not stratified by ethnicity, overall mean reported; w, weeks; m, months; *italics*, components received by all participants; n, number of participants; IV, intervention; C, control.

TABLE 3

Barriers and facilitators to accessing therapies

Psychological therapies	
Eisdorfer, 2003	**Facilitators:** Targeted family structure: Cuban-American "Familismo"; Bilingual/bicultural staff; Spanish/English materials. **Barriers:** costly; clinical implementation difficult
Gallagher-Thompson, 2003	**Facilitators:** English/Spanish educational materials, advertisements, assessments; informal discussions; recruitment with Latin American organisations; local community setting; outcome measures always conducted in home/confidential place; classroom-like setting reduces stigma; use of homework assignments/chalkboards; ended with "graduation ceremony": family/friends invited. **Barriers:** Care needed in absence.
Gallagher-Thompson, 2007	**Facilitators:** in-home (Chinese caregiver's preference); educational approach; focus group; recruitment incentive; bilingual/bicultural staff; flexible language use (Mandarin/Cantonese/English); translators aware of dialects/socio-political/historical language context.
Gallagher-Thompson, 2008	**Facilitators:** Spanish/English materials; peer support: normalise difficulties; discussed difficulties/obstacles first 30-mins; embedded short relaxation techniques; bilingual/bicultural staff; sessions provided materials; reinforce learning.
Gallagher-Thompson, 2010	**Facilitators:** Materials in Mandarin/ English; Bilingual/bicultural staff; educational approach; DVD use enquiries served as reminder phone calls. **Barriers:** Generic non-personalised DVD; Minimal contact.
Gonyea, 2012	**Facilitators:** Adopted language to minimise stigma, e.g. 'memory problems' versus 'dementia'; described intervention as educational (versus therapeutic); community/local setting; small informal/highly interactive groups; food/refreshments decisions shared/discussed; group leader arrived early/left late; certificate of completion; psychoeducational control provided; waiting list causes frustration/considered disrespectful by agencies; experienced with Latin American communities and highly skilled group facilitators. **Barriers:** Care needed in absence; out of home: limited caregiver availability.
Glueckauf, 2012	**Facilitators:** Reimbursed for travel/telephone expenses; peer support; telephone; older caregiver preference; low cost; caregiver-specific goals identified; emphasis on education. **Barriers:** Out of home; Care needed in absence.
Multi-component	
Belle, 2006	**Facilitators:** Materials translated to Spanish considering regional variations; certified cultural sensitivity training; bilingual/bicultural staff recruiting Latin American/Hispanic caregivers. **Barriers:** Reliant on some literacy
Burgio, 2003	**Facilitators:** In-home; African American caregivers reluctant to speak up in groups; bilingual/bicultural staff; information ease-of-access: skills-training notebook; videotape demonstrating techniques in simple language video players provided; communication training; assertiveness and addressing racism with professionals. **Barriers:** Reliant on some literacy; high cost; staff training, materials
Chodosh, 2014	**Facilitators:** All care managers native Spanish speakers; local Alzheimer's association partnership; all materials translated to Spanish; purchased mobile phones with unlimited minutes.

	Barriers: Staff not same-background as caregivers; High cost; mobile phones
Czaja, 2013	**Facilitators:** In-home convenient for caregivers; peer support; videophone support groups normalise caregiving difficulties; encourage sharing of coping strategies; reduce stigma. All materials/measures translated; bilingual staff for Spanish speakers; videophone installed in-home; in-home access to seminars/information (via videophone); provided technical support; videophone English/Spanish features; access for family members/network. **Barriers:** Reliant on some literacy; technical difficulties off-putting; high cost; videophone technology and installation
Winter, 2006	**Facilitators:** Women's organisation recruited/supported; Peer support: normalise difficulties. **Barriers:** Difficulty arranging group sessions, limited caregiver availability; telesupport session $28.50 per caregiver; care needed in absence
Educational	
Gallagher-Thompson, 2015	**Facilitators:** Spanish materials; fotonovela actors also Mexican; empowering, increase self-esteem; ease of access; hard copies; materials publicly available; word-of-mouth; elementary level language used; non-invasive. **Barriers:** Reliant on active help seeking; Reliant on some literacy.

Ordered alphabetically in respective groups.

SUPPLEMENTARY TABLE 1

Included studies' personnel

Study code	Delivered by:
Belle, 2006	Certified interventionists with at least a bachelor's degree, whom some of delivered interventions in Spanish.
Burgio, 2003	Research personnel as interventionists and assessors however, it was ensured that dyads did not have the same individual conducting both processes. Eleven interventionists were trained and certified by the REACH Coordinating Center.
Chodosh, 2015	Social workers trained by a nurse-scientist and geriatrician with either a bachelor's or master's level degree, previous experience of working with Hispanic populations and bilingual. All care managers had a Latino cultural background. Social workers attended a weekly meeting to discuss difficulties.
Czaja, 2013	All assessors and interventionists were trained, taped during sessions and received feedback before certification. Staff also received a detailed manual and weekly supervision meetings. Interventionists taught problem solving strategies to manage stress and problem behaviours. Bilingual staff were used for Spanish speaking participants.
Eisdorfer, 2003	Bilingual and certified assessors and interventionists who were given training and detailed treatment manuals. Throughout the study they were monitored and provided with regular feedback on performance.
Gallagher-Thompson, 2007	Bilingual/bicultural interventionists whom received in-depth treatment manuals and regular supervisory sessions to ensure adherence.
Gallagher-Thompson, 2010	The intervention DVD was put together with the help of an advisory committee of Chinese professionals experienced in working with dementia patients and their families. DVDs were filmed in Mandarin with English subtitles.
Gallagher-Thompson, 2003	Certified interventionists had weekly supervision, detailed manuals, interventions audiotaped and rated. 50% of interventionists were bilingual or bicultural.
Gallagher-Thompson, 2008	Postdoctoral fellows, advanced graduates in psychology or related fields whom had Latino/Hispanic bilingual/bicultural backgrounds.
Gallagher-Thompson, 2015	Research assistants with relevant bilingual or bicultural background.
Gonyea, 2012	Bilingual social workers with experience of working in Latino communities.
Glueckauf, 2012	Four African-American counsellors, with at least a master's degree in a counselling related profession and a year's experience, however had no experience in running a formal CBT workshop. Counsellors attended two six-hour training workshops over two months carried out by authors. Thereon, all counsellors received weekly one-hour consultation sessions with the authors where they received feedback on their audio recordings of their CBT sessions which was reviewed by two independent trained coders.
Winter, 2006	Trained social workers

SUPPLEMENTARY TABLE 2:

Meta-regression: Sources of heterogeneity for interventions* for caregiver depression in ethnic minority groups

Study characteristic	Number of studies	β (SE)	(95% CI)	p value
Intervention type				
Psychological	7	REF	-	
Educational	1	-0.07 (0.22)	(-0.55, 0.41)	0.75
Multi-component	5	0.02 (0.13)	-(0.27, 0.31)	0.87
Instrument used to assess depression				
CESD-10	3	REF	-	
CESD-20	10	-0.08 (0.13)	(-0.36, 0.20)	0.54
Peer support				
Present	9	REF	-	
Not present	4	0.01 (0.14)	(-0.30, 0.32)	0.97
Ethnicity				
Hispanic/ Latino	6	REF	-	
African American	4	0.07 (0.14)	(-0.24, 0.39)	0.62
Chinese	2	-0.05 (0.21)	(-0.52, 0.41)	0.80
Hispanic & Black American (both)	1	0.05 (0.05)	(-0.53, 0.63)	0.86
Person delivering the intervention has same bicultural/ bilingual background as recipient				
No	2	REF	-	
Yes	11	-0.06 (0.14)	(-0.37, 0.25)	0.68
Quality of study				
Strong	10	REF	-	
Moderate	3	0.06 (0.06)	(-0.35, 0.48)	0.75
Control setting controls for contact time and type of delivery adequately				
No	6	REF	-	
Yes	7	-0.01 (0.12)	(-0.28, 0.26)	0.91

**I^2 or proportion variance due to heterogeneity was 0.0% across all variables*

SUPPLEMENTARY TABLE 3

Quality assessment ratings for included studies as measured by The Effective Public Health Practice Project Quality Assessment Tool (EPHPP)

STUDY	EPHPP COMPONENT RATINGS §						GLOBAL RATING
	SELECTION BIAS	STUDY DESIGN	CONFOUNDERS	BLINDING	DATA COLLECTION METHOD	WITHDRAWALS AND DROPOUTS	
Belle et al., 2006	1	1	1	1	1	1	**1**
Burgio et al., 2003	2	1	1	3	1	2	**2**
Czaja et al., 2013	3	1	1	1	1	2	**2**
Eisdorfer et al., 2003	2	1	1	2	1	2	**1**
Gallagher-Thompson et al., 2003	2	1	1	2	1	2	**1**
Gallagher-Thompson et al., 2007	2	1	2	2	1	2	**1**
Gallagher-Thompson et al., 2008	2	1	1	2	1	2	**1**
Gallagher-Thompson et al., 2010	2	1	1	2	2	2	**1**
Gallagher-Thompson et al., 2015	2	1	2	2	1	1	**1**
Gonyea, 2012	2	1	2	2	1	2	**2**
Glueckauf et al., 2012	3	1	1	2	1	2	**2**
Winter & Gitlin, 2006	2	1	2	2	1	1	**1**

§RATINGS: 1 = STRONG, 2 = MODERATE, 3 = WEAK

SUPPLEMENTARY MATERIAL 1

Example search strategy: MEDLINE

1. exp minority Groups/
2. (minorit* adj4 (ethnic* or group* or racial or communit* or background*)).tw
3. (BME or BAME or BMER or BAMER).tw
4. ethnic groups/
5. (ethnic* or racial).tw
6. exp "emigration and immigration"/
7. (migra* or immigra*).tw
8. refugees/
9. (refugee* or asylum seek*).tw
10. (multicultural or multi cultural or multilingual or multi lingual or multiethnic or multi ethnic).tw
11. CALD.tw
12. ((cultural* or linguistic* or ethnic* or racial* or communit* or background*) adj5 divers*).tw
13. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12
14. ethnic groups/
15. (Hispanic* or Latin* or Bra?ilian* or Mexican* or Cuban* or Colombian* or Puerto Rican* or Salvadoran*).tw
16. (Asian* or Turk* or India* or Pakistan* or Bangladesh* or Chinese).tw
17. (G?psy or g?psies or Traveller*).tw
18. (Black adj 5 (Caribbean or African)).tw
19. (Afr* adj2 Caribbean*).tw
20. (people of colo?r or colo?red).tw
21. (Islam* or Hindu* or Sikh* or Jew*).tw
22. Native adj5 (America* or India* or Canad* or Australia*).tw
23. 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22
24. exp dementia/
25. (dementia or frontotemporal or pseudodementia or Alzheimer* or Lewy bod* or multi infarct or multiinfarct).tw
26. 24 or 25
27. community health services/
28. program evaluation/
29. health promotion/
30. community based.tw
31. community adj5 (program* or care or support*).tw
32. exp volunteers/ or volunteer*.tw
33. (psychosocial adj5 (campaign* or project* or intervention* or program* or package* or strateg* or drive* or system*)).tw
34. caregivers/

35. ((support* or help* or aid* or assist* or train* or skill* or therap*) adj5 (carer* or care-giver*)).tw
36. problem solv*.tw
37. exp psychotherapy/ or psychotherapy*.tw
38. exp counseling/ or counsel?ing.tw
39. CBT.tw
40. (cognitive adj3 behavio?r*).tw
41. (behavio?r* modification or behavio?r* therapy or behavio?r* activation).tw
42. (interpersonal therap* or inter personal therap* or IPT).tw
43. (psychoeducation* or psycho education*).tw
44. (sociotherap* or socio therap*).tw
45. "quality of life"/ or quality of life.tw
46. cultural competency/
47. health education/
48. (education* or awareness or recognition* or understanding*).tw
49. Attitude to health/
50. (attitude* or belief*).tw
51. social stigma/
52. (stigma* or shame).tw
53. exp patient advocacy/
54. (advoca* or befriend* or advice or advisor* or signpost* or link worker* or outreach).tw
55. (service adj5 navigat*).tw
56. self-help groups/
57. (self help group* or support group*).tw
58. 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57
59. 13 or 23
60. 26 and 58 and 59